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# Genio Dementia Programme

## Evaluation of Year 1

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“ DEMENTIA HAS TRADITIONALLY BEEN CONSIDERED PART OF NORMAL AGEING AND HAS NOT BEEN A PUBLIC HEALTH PRIORITY, MAKING IT EVEN EASIER TO IGNORE, PARTICULARLY IN RELATION TO RESOURCE ALLOCATION. ”



## Introduction

**DEMENTIA** is a chronic, progressive disease, mainly affecting older people, eroding their cognitive and functional abilities and social skills, and at times, impacting on their mood and personality. Dementia is often overwhelming both for the person with dementia and for their family and carers. Dementia is also a global phenomenon. It is estimated that there are 44.35 million people world-wide living with dementia in 2013 (Prince et al., 2013). These numbers are projected to double every 20 years to 135.46 million by 2050 (World Health Organisation, 2012). The incidence of dementia is estimated at 7.7 million new cases per year, or one new case every four seconds. Life-expectancy is reduced for people with dementia, although the exact impact is difficult to estimate, as people tend to die *with* dementia rather than die *of* dementia. The estimated cost to society of dementia worldwide is US\$604 billion.

Estimating the number of people with dementia in Ireland, as elsewhere, has proven difficult in the absence of national prevalence rates. Formal

diagnosis of dementia in Ireland is not common place and there is no national register of people with dementia. More recently, based on the 2006 census data, Cahill and colleagues estimated that there are currently 41,740 people with dementia in Ireland (Cahill et al., 2012). By combining CSO population and labour force predictions with European estimates of age and gender specific prevalence of dementia, it is predicted that over 140,000 people in Ireland will have dementia by 2041.

Dementia in Ireland is associated with poor diagnosis, stigma, and lack of awareness among the general public. Not surprisingly, perhaps, service provision has been, as a consequence, badly structured, poorly funded, and weakly integrated. The tireless work of those charged with providing care services to people with dementia is largely unsupported, within a system that does not place a priority on the intrinsic needs of people with dementia. Similarly, family carers can often feel isolated and vulnerable as they seek to do their best for the person under their care. Moreover, although the concept of



personhood in dementia is now almost universally accepted, person-centred care in Ireland for people with dementia is the exception rather than the rule. The principles of empowerment, inclusion, integration and equity, which are now routinely associated with disability, and increasingly in mental health, have not been applied to people with dementia. Dementia has traditionally been considered part of normal ageing and has not been a public health priority, making it even easier to ignore, particularly in relation to resource allocation. But this is changing: the World Health Organisation in 2012 called on governments worldwide to make dementia a public health priority (World Health Organisation, 2012). In December 2013, a G8 summit in London brought additional focus to the global challenge of dementia and the summit concluded by making a commitment to build an international effort to approach the problem of dementia through research and innovation, leadership, and cross-sectoral partnerships.

In Ireland, there have been a number of important developments in recent years

which have focused more attention on dementia, in parallel with recent international trends. The *Creating Excellence in Dementia Care* report by Cahill and colleagues in 2012 outlined in great detail the major issues in relation to dementia care in Ireland and has provided the basis for the upcoming National Strategy for Dementia, due to be published later in 2014. Philanthropic support from Atlantic Philanthropies has also succeeded in raising the capacity of the dementia sector in Ireland to engage with people with dementia in a number of different ways including advocacy, research, education, policy development, and, increasingly, service provision.

More recently Genio, which is a non-profit organisation dedicated to bringing together government and philanthropy to develop, test, and scale cost-effective ways of supporting people who are disadvantaged to live full lives in their communities, has supported and facilitated considerable investment in dementia in Ireland. The first tranche of investment by

Genio in dementia occurred in 2012, when Genio received funding from the Atlantic Philanthropies and the Health Service Executive (HSE) to develop and test new service models that would improve the range and quality of community-based supports for people with dementia in four different regions.

This report examines the workings of the Genio programme in 2013, the first year of operation, and its impact in relation to the public awareness of dementia, diagnosis, community-based supports, integrated provision, and sustainability. The report also covers the relevance and implications of the Genio programme over the coming years for public policy and its role in heralding and showcasing a new, person-centred approach to dementia care in Ireland. The report draws on information provided by Genio, information-gathering visits to each site to meet with key personnel, and a structured questionnaire completed by each site as part of this evaluation process (see Appendix A), which invited the sites to reflect on their progress in the first year.





# 2

## Current Realities of Dementia Care in Ireland

**WHILE** no comprehensive prevalence studies on dementia have been carried out in Ireland, the application of Euro-CoDe age/gender specific dementia prevalence rates to the 2006 Census of Population data suggests that there are currently 41,740 people with dementia in the country. An estimated 3,583 of these people (approximately 8.5% of all people with dementia) have early onset dementia (occurring in people under 65 years of age) and most of these are likely to be men. There are also clear regional differences in prevalence rates for dementia and simply looking at the age structure of local populations can tell a lot about the potential prevalence of dementia in that area and the need to structure services accordingly. A tentative extrapolation of incidence rates to the elderly population in Ireland suggests that currently approximately 4,000 new cases of dementia arise in the general Irish population every year (Cahill et al., 2012).

There are an estimated 26,104 people with dementia currently living at home in the community; most of these do not have a formal diagnosis, many are not aware that they have the disease and few are likely to be in contact with the health and social care system. There are an estimated 50,000 family carers in Ireland looking after someone with at least one of six specified symptoms of dementia (O'Shea, 2003): for example an estimated 25,000 carers are looking after someone with marked forgetfulness on a regular or occasional

basis, while 15,000 people are looking after someone with confusion to the point of interfering with everyday life. An estimated 14,266 people with dementia live in various public and private long-stay facilities across the country, including 537 people aged less than 65 years. Official statistics on the number of people with dementia in long-stay care settings suggests less than half that figure, but most commentators accept the higher estimate.

The cost of dementia in Ireland has been estimated at just over €1.69 billion per annum, 48% of which is attributable to informal care provided by family and friends to those living with dementia in the community (Connolly et al., 2014). A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. Increasingly, however, the burden on the acute care sector is being recognised (Nolan, 2007; Hickey et al., 1997; Cowdell, 2010). People with a diagnosis of dementia tend to have a significantly longer length of stay in hospital than those without dementia, a finding that holds across a number of co-morbidities.

The main bulk of care for people with dementia is provided in their own homes in the community mostly free of charge by adult children and spouses, many of whom are frail and older themselves. Caring for a person with dementia compared with other caring

roles, places much greater demands and strain on family members (Zarit et al., 1999; Ory et al., 1999; Pinquart and Sorensen, 2003; Bertrand et al., 2006). The family caregiver of a person with dementia in Ireland is much more likely to be providing significant levels of care, sometimes struggling to cope with distressing, challenging behaviours, leading to considerable emotional and psychological strain (O'Shea, 2003; O'Shea, 2007).

There is now convincing evidence that early accurate diagnosis of dementia is critical to best practice in dementia care and yet across most European countries, including Ireland, dementia remains largely invisible and under-diagnosed (Leifer, 2003; Lopponen et al., 2003; Bamford et al., 2004; Carpenter and Dave, 2004; Wilkins et al., 2007) across all care settings. The benefits of early diagnosis to the individual include the fact that he/she may still be able to actively participate in short and long-term care planning and engage in decision-making about important issues, including drug treatments, management of legal and financial affairs, and service options. In some instances, getting a diagnosis may be psychologically beneficial since the person experiencing the symptoms may still have insight and may be anxious and under pressure by spouse or relatives for what is perceived by them as forgetful, unreasonable, inappropriate, or decidedly "odd" behaviour.

## 2 Current Realities of Dementia Care in Ireland

In about one third of cases, drug therapy may help to delay the progression of the disease (Overshott and Burns, 2005). Informing and educating people with dementia about the condition can enable them and their caregivers to adjust and adapt (Connell et al., 2004; Derksen et al., 2006). These benefits in turn may improve the individual's quality of life and reduce caregiver stress. Furthermore, and at a societal level, early recognition, timely diagnosis, and appropriate community-based intervention can reduce healthcare expenditure by delaying nursing home

who participated in the National Dementia Summit in Ireland in 2011 (Alzheimer Society of Ireland, 2011) described how even after getting a diagnosis, they felt that they were left to their own devices to source and access appropriate services, if indeed they existed. While there is no consensus about what constitutes a good model for early support services for those newly diagnosed with dementia and their carers, information services and counselling and emotional supports are key elements in the early stages (Cahill et al., 2012).

13% of people over 65 years of age in Ireland are in contact with public health nursing services (McGee, 2005). There is a positive correlation between age and use of public health nursing services with almost a quarter of people over the aged of 80 availing of this service (Normand et al., 2011). Since age and dementia are also correlated it is safe to assume that public health nurses in Ireland are in contact with a significant number of older people with dementia. In many instances public health nurses are the gate-keepers to other community care services such as home help, meals on wheels, day care and other respite care. They also liaise with family doctors (GPs), practice nurses, hospitals, hospices, and other health service providers and organise and co-ordinate other services often considered vital to maintaining older people at home in the community.

“ WHEN RESOURCES ARE TIGHT, IT IS MUCH EASIER TO REDUCE SERVICES TO PEOPLE WITH DEMENTIA LIVING AT HOME, OR NOT PROVIDE SERVICES AT ALL, THAN IT IS TO CUT BACK ON HOSPITAL-BASED SERVICES THAT ARE MUCH MORE VISIBLE AND POLITICALLY SENSITIVE. ”

admission (Mittelman et al., 1996; Turner et al., 2004; Leifer, 2003). Despite GPs themselves acknowledging the benefits of early diagnosis (Cahill et al., 2008), diagnosis in Ireland is the exception rather than the rule and the vast majority of people with dementia remain without a diagnosis.

A diagnosis is but a first step on the pathway to care for dementia. Several people with dementia and their families

Community-based nurses can play a key role in helping to educate people about the risk factors for dementia and about lifestyle choices that can be adopted to minimise the risk of developing a dementia in later life. They also provide front line care to people with dementia, both diagnosed and undiagnosed. Although records are currently not being kept on the number of Irish people with dementia who avail of public health nursing services, about

Unfortunately, in Ireland today there are no public health nurses with a dementia-specific remit and their workload remains extremely diverse, thereby likely 'crowding out' care to people with dementia. The public health nurse in Ireland is a "Jack of all Trades" so to speak (Nic Philibin et al., 2010): expected to provide from the cradle to the grave a myriad of different professional services (post-operative care, medication management, dressings changing). It is likely that only a fraction of people with

dementia in Ireland are known to public health nurses and that the service as it currently operates is not sufficiently flexible to meet the complex, chronic and fluctuating needs of people with a moderate to advanced dementia. Nor are public health nurses likely to have received specialized training in dementia assessment or care.

In Ireland, the Home Help Service and Home Care Support Schemes, otherwise known as Home Care Packages (HCPs), are two important home care services developed to assist older people including those with dementia to remain in their own homes for as long as possible. These services are delivered either directly through the HSE, through community and voluntary organisations or through private providers. Dementia-specific HCPs are also delivered through voluntary organisations such as Alzheimer Society Ireland (ASI) whereby a trained dementia care worker is assigned to a person with dementia in the community for a designated number of hours per week.

However, one of the resounding weaknesses of Irish statutory home care services compared with those developed and delivered in other countries (such as the UK, Norway, Sweden, Denmark, France and Australia) is that these services are not underpinned by legislation and are not provided on a statutory basis.

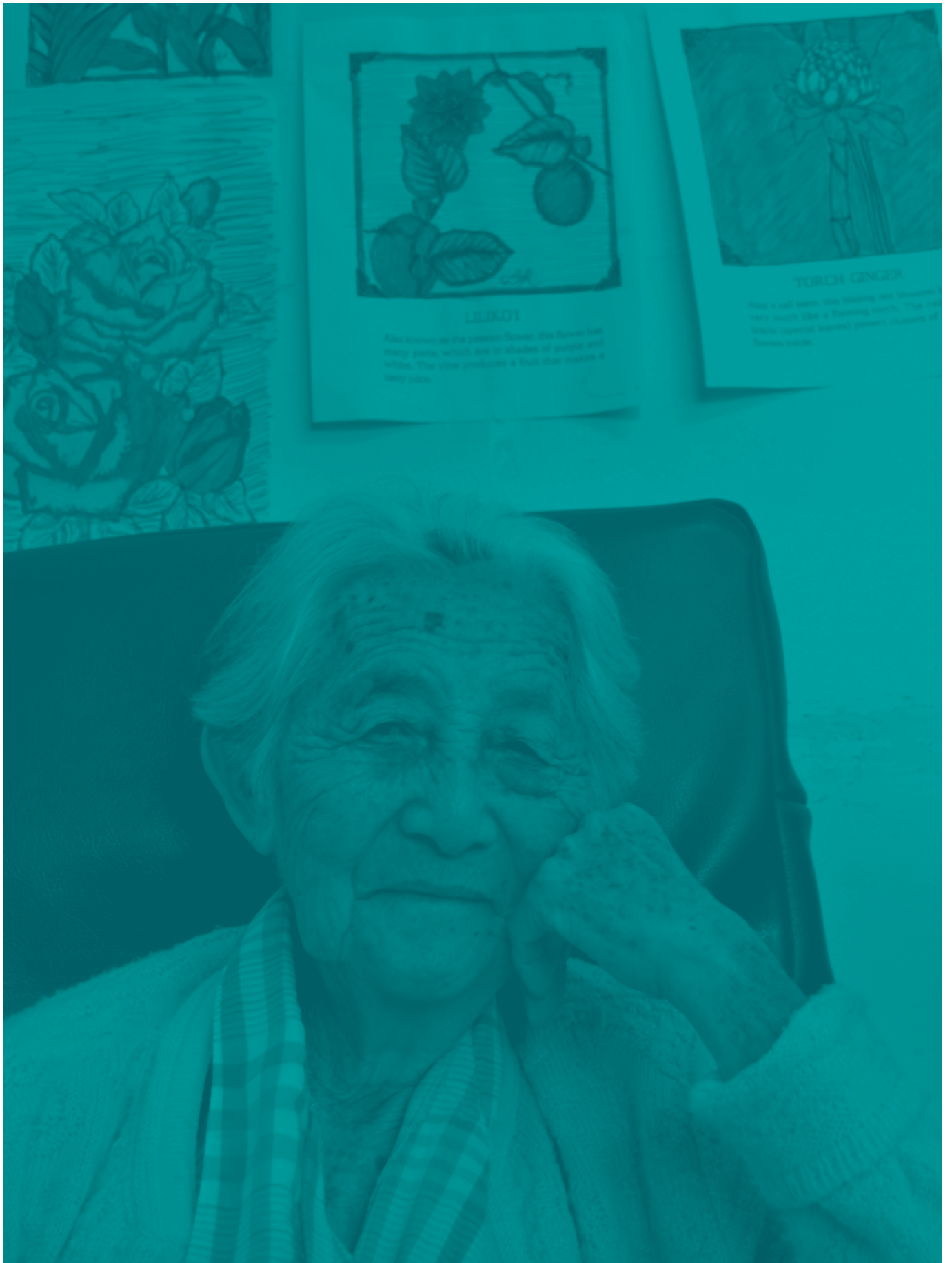
Accordingly, there is no onus on the health and social care system to provide services to people with dementia in need. When resources are tight it is much easier to reduce services to people with dementia living at home, or not provide services at all, than it is to cut back on hospital-based services that are much more visible and politically sensitive. On the demand side, lack of knowledge and confusion about entitlements to services combine to exacerbate supply-side inadequacies leading to significant gaps in home care service provision to people in need. There are also gross inequities across the country in relation to service delivery with considerable variation in the type and amount of home care services available (PA Consulting Group, 2009). In some areas, people with dementia receive very few in-home formal support services and certain schemes, which have the potential to reduce caregiver burden and prolong home-living such as Home Care Packages, lack the flexibility and specificity to address the fluctuating needs of many people with a moderate and severe dementia.

Day care and respite care also remain under-developed in Ireland, their potential unrealised as part of the holistic care of people living at home with dementia. Even where day services exist, they may not always be used by people with dementia. Lack of knowledge about their availability,

geographical distance from day care services, and transport problems, including high transport costs, are all factors contributing to the low levels of utilisation of day care services by people with dementia. There is no doubt that day care, like respite care, is underprovided in Ireland, given the potential benefits associated with its use (Cahill et al., 2012).

The recent period of austerity has not been responsible for the relatively low level of government support for community-based resources for dementia in Ireland. Even when resources were plentiful, investment in dementia care has been historically weak, particularly in relation to community-based care. Dementia has, for a long time now, been a hugely neglected, under-funded and under-prioritized health issue in the Irish health and social care system, notwithstanding the current commitment by government to produce a National Dementia Strategy, for the first time, in 2014. There is currently no protected dementia-specific budget available to support the development and delivery of statutory community-based dementia services. Health and social services are financed from the same budget, hence dementia spending is generally squeezed out by medical and hospital services on one side and residential care spending on the other.







# 3

## Dementia Internationally

**DEMENTIA** is a global public health issue and poses one of the greatest challenges for 21<sup>st</sup> century society. In the last decade we have witnessed a burgeoning political interest in dementia, beginning with the Kyoto Declaration in 2004, which identified 10 “minimum actions” required to provide for the care of people with dementia. These included providing treatment in primary care, providing care in the community, educating the public about dementia to combat the stigma associated with the disease and involving communities and families in policy making and service development.

The World Health Organisation recently published a report entitled *Dementia: a public health priority* to focus attention on dementia worldwide, encouraging all governments to set dementia as a national health priority (World Health Organisation, 2012). Over the last 10 years, national governments have begun to give increasing attention to dementia. Driven initially by President Sarkozy, France have been leaders in this drive, publishing their first National Dementia Strategy in 2008, pledging 1.6 billion to the five year programme. During the French presidency of the EU, Sarkozy made dementia a priority and thus inspired other governments to follow suit. The National Alzheimer’s Project Act was signed into law by U.S. President Barack Obama in January 2011, requiring the development of a national strategic plan in the United

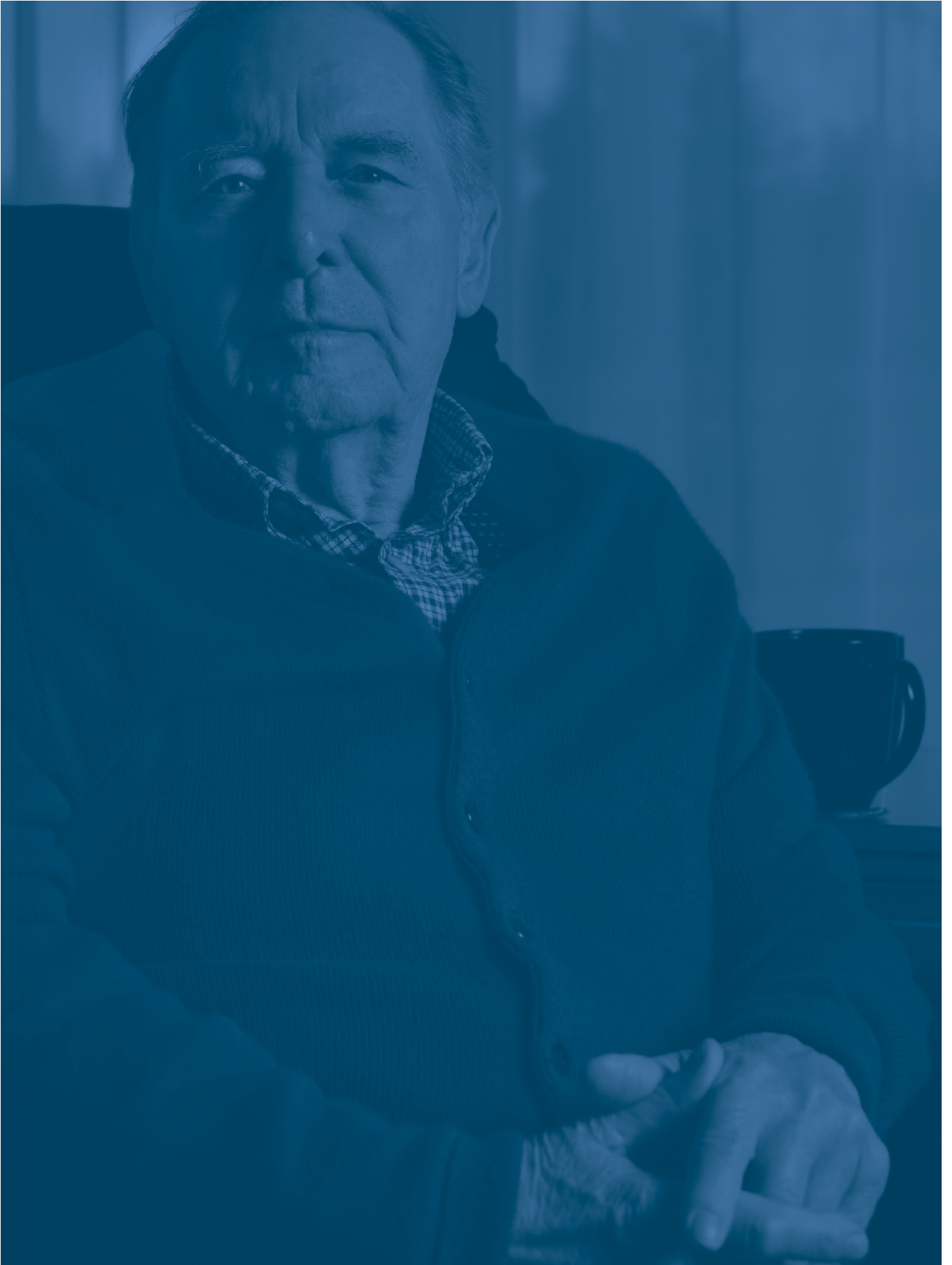
States to address the Alzheimer’s crisis and coordinate efforts across the federal government. In 2012, David Cameron in UK gave a seminal speech on the need to tackle the national crisis of dementia and in December 2013, a G8 summit on dementia was held in London.

A number of countries, including Ireland, are currently developing national dementia plans while other countries have published their first national plans within the last two years (e.g. Finland, 2012) or have regional plans, as health and social care is decentralised (e.g. Belgium, Australia). However, low and middle income countries, where resources are scarce and where most growth in dementia will occur in the next 20 years, are lagging behind in developing national plans.

In a review of 14 national and subnational dementia policies and plans by the WHO in 2012, similar themes emerged from different countries. The top priority was improved diagnosis (10 countries), with significant focus also on support for carers (8 countries), provision of information for the PWD and carers (7 countries), and 6 countries listed each of education and training for care staff, interdisciplinary communication and continuum of care, increased research funding and increased public awareness as top priorities.

On the ground, various new initiatives are being implemented, for example,

the Dementia Friends Champions initiative in the UK, aiming to recruit 100,000 volunteers to deliver dementia awareness sessions to the public, with a goal to educate 1 million by 2015 on how they can make a positive difference to the lives of people with dementia. In Australia, the Heart Foundation partners with Alzheimer’s Australia to help people with dementia to get involved in active, social walking. In Scotland, Dementia Practice Coordinators, the key point of contact for a PWD upon receiving a diagnosis, work with the PWD and their family/carer to identify supports that will enable the PWD to continue to be fully included in mainstream community activity. In Japan where the word for dementia had negative connotations, the government officially changed the word and launched a ten year nationwide campaign to raise public awareness and understanding of dementia, with 4 million people already trained dementia volunteer supporters.



# 4

## A Social Model of Dementia

**NATIONALLY** and internationally the trend is towards a social model of dementia. There is much, therefore, to be learned from a brief examination of the social model of disability, and of the lessons that might be learned from that source that could contribute to a better understanding of the changes that will have to take place to make dementia a social phenomenon as much as a medical condition. All the more so since Genio in Ireland has had much success in supporting the social model of disability, and more recently through its funding of the Recovery Model in mental health. Dementia is still rooted in a medical model and the current engagement by Genio in the dementia space is based on a desire to move the care system towards a personalized individualized approach that focuses on personhood, autonomy, empowerment, and social connectivity for people with dementia.

Social health for older people comprises a definition of individual well-being that is distinct from both physical and mental health, but impacts on both. Social health is concerned with older people's ability to function as members of the community and includes measures of people's connectedness to others in terms of interpersonal interactions and social participation. The social model distinguishes impairment from dependency. It refers to the possibility that dependency is created through

social forces and social structures impacting on the ability of older people to take control of their own lives (Townsend, 1981). Economic deprivation can also prevent people being able to participate meaningfully in economic and social life, both absolutely and relative to prevailing social standards. The disability movement has been much more successful than the ageing sector in identifying and overcoming social obstacles to independence and in promoting social policies that respect the rights of people with disabilities. But there has traditionally been little focus in the disability movement on the specific needs of older people who develop disabilities in older age. Within the ageing sector, and dementia in particular, older people are often excluded from decision-making. They are consulted less often when it comes to service provision or placement decision-making. Their problems tend to be medicalised and decisions made for them.

In a study on ageing and disability conducted for the now dissolved National Council on Ageing and Older People, Murphy and colleagues found that older people with disabilities were conscious of the limitations imposed on their autonomy and independence by social forces and social structures (Murphy et al., 2007). Some of them spoke about ageism, being treated as second-class citizens in their

daily life and having decisions made for them, not by them. They did not have entitlements to services but were dependent on the vagaries and vicissitudes of the health and social care system and the budgetary system that underpinned resource allocation in this area. Many participants also spoke about the absence of information as a barrier to accessing services and to participation generally. Too many people simply did not know what their entitlements were.

been achieved in the context of recent equality legislation and through the Disability Act 2005, but much more remains to be done to find some common ground between older people who develop dementia in later life and those living with a disability for a most of their lives who are the focus of the disability movement. People with dementia are routinely denied voice that would be unthinkable in the disability sector. There is a real need for disability awareness and equality work with

capture disability relationships through a single version or theory of ageing. The lesson from the social model of disability is that ageing cannot be represented in terms of a deficit model that sees old age simply as a medical problem. But neither can ageing be captured by a heroic model that implies the denial of ageing and the continuation of a life of unlimited opportunities in civic and social life. People with dementia may want to be independent, particularly in the early stages of the disease, but most are conscious of the range of personal and social limitations and constraints imposed by their condition. There is a post-medical, post-social world where biological, psychological and social conditions combine in a complex way to determine well-being and quality of life. Dementia cannot, therefore, be understood without a forensic and ethnographic examination of the person and the community within which they live. The task is to provide maximum opportunities for choice, autonomy and empowerment within the limitations associated with the disease.

“ DEMENTIA IS STILL ROOTED IN A MEDICAL MODEL AND THE CURRENT ENGAGEMENT BY GENIO IN THE DEMENTIA SPACE IS BASED ON A DESIRE TO MOVE THE CARE SYSTEM TOWARDS A PERSONALIZED INDIVIDUALIZED APPROACH THAT FOCUSES ON PERSONHOOD, AUTONOMY, EMPOWERMENT, AND SOCIAL CONNECTIVITY FOR PEOPLE WITH DEMENTIA. ”

There are strong arguments, therefore, for the adoption of a broader definition of dependency that incorporates physical, mental, social, and economic functioning. There is much that the dementia sector can learn from the disability movement in the development of a social model. Much has already

advocacy groups representing older people and with agencies providing services to older people with dementia (Priestley and Rabiee, 2002).

An important question is whether there are particular age-related aspects to disability and whether it is possible to

One of the advantages of a person-centred approach is that it allows consideration of all of the factors that make life different for an older person with dementia. Barriers to participation can be identified and addressed. Ageism, for example, is a pervasive fact for older people in Ireland (Basten



et al., 2002). It leads to prejudice and discrimination and ultimately may contribute to a different experience between younger and older people with disability. Ageism may exacerbate the potential for exclusion that dementia presents. In an environment of sustained retrenchment in health and social care spending, people with dementia may be placed at the end of the queue for health and social care services. Rationing is most problematic for older people when it is covert (Dey and Fraser, 2000). In Ireland, there is some evidence of rationing by age through delay rather than through overt denial of services (Murphy et al., 2007). One of the key features of being old with a dementia in Ireland seems to be that of perpetual waiting: people with dementia wait for diagnosis, services, and appointments that never come.

Paternalism also impacts negatively on the lives of people with dementia in a way that would not be tolerated in the disability sector. Paternalism disables people with dementia by taking away decision-making too early in the disease. Decisions are made on behalf of people with dementia that may or may not be in their best interests. Paternalism almost certainly leads to people being admitted to residential care earlier than they should. Risk is prioritised over freedom, leading to the exclusion of people with dementia from the normal networks, interactions,

and vagaries of human life. Even more worryingly, people with dementia are spoken of or about, rather than with, thereby denying them the basic humanity that distinguishes normal human interaction.

The negative perceptions of individuals and society regarding dementia that finds expression in ageism and paternalism, may lead to the isolation of people with dementia and their carers (World Health Organisation, 2012). This is reinforced by the widespread assumption that people with dementia cannot take part in ordinary activities and that they have no quality of life or capacity for pleasure. While the symptoms associated with dementia affect the way a person with dementia interacts with others, and some activities may be inappropriate as a result, there are many activities, sometimes with adjustments to take account of the disability, in which they can participate and enjoy fully (World Health Organisation, 2012). Both people with dementia and their carers will benefit from continuing, whenever possible, to engage in as many activities as they can. Moreover, people with dementia should be encouraged to make decisions or partake in decisions that affect them for as long as possible, to maintain their dignity and self-esteem. This is the true meaning of the social model of dementia.





# Genio Dementia Programme

**A NON-PROFIT** organisation, Genio brings together government, philanthropic and non-profit sectors to support social innovation in Ireland that has a lasting impact. Genio focuses on those who are socially excluded, to enable them to live in their own homes and to be active and valued members of their local community. Genio is currently operating in the fields of disability, mental health and dementia, supporting over 210 projects.

In 2012, Genio received funding from Atlantic Philanthropies (2.3 million euro) and the HSE (2 million euro) for a Dementia Programme. The aims of the programme are to:

- Develop and test new service models for people with dementia that would improve the range and quality of community-based supports for people with dementia
- Influence public policy and investment in this area
- Build the leadership in the field that is necessary to capitalize on the potential of the proposed national dementia strategy

The Genio Dementia Programme focuses on six main areas of activity:

**Demonstration areas:** Developing the provision and integration of person-centred, community-based supports to people with dementia and their families/carers that enable them to live longer

within their local community – thus diverting them from institutional care.

**Capability building:** Supporting services and their personnel in the four programme areas to work with a person-centred focus and in a more collaborative and integrated way with enhanced awareness and skills; identifying barriers and solutions around integrative working.

**Community supports:** Using a community development approach to identify and harness existing community resources (including all resources, not just those with a focus on older people), to develop community-based responses which use local strengths and resources to meet local and individual need. This will build a range of community supports across each area.

**Developing best practice:** Applying and testing principles and best practice models from other sectors including disability, mental health and children's services; for example, person-focus, early intervention, prevention, community integration, consultation and participation.

**Learning network:** Developing a learning network across the four programme areas and beyond to share learning in a systematic way and to create a learning support for further expansion of the programme.

**Collecting evidence:** Collecting quantitative and qualitative data from the demonstration areas to evaluate the community support models, to feed into learning networks that will be developed to extend models of community support, and to inform the development of the National Dementia Strategy.

The Genio approach is aligned with government policy, which emphasises the provision of services that support older people to remain at home, living full lives for as long as possible, and supporting families and local communities in this aim. Unfortunately, the rhetoric of government policy has not always been supported by resource allocation directed towards community-based solutions. Consequently, existing services have not matched the needs of people with dementia and their family carers.

## Genio Dementia Sites

In late 2011, Genio invited expressions of interest from consortia for inclusion in the Dementia Programme. Having undergone an in-depth and competitive screening and evaluation process, four regional projects were selected for funding in Kinsale, South Tipperary, Stillorgan-Blackrock, and Mayo (see Table 5.1 and 5.2 for summary outlines).

**TABLE 5.1** GENIO DEMENTIA SITES AT A GLANCE

	Kinsale	South Tipperary	Stillorgan-Blackrock	Mayo
<b>Demographics</b>				
PWD in region	250	1,011	500	1,692
Total population (% with dementia)	23,572 (1.1%)	88,441 (1.14%)	41,848 (1.19%)	130,000 (1.4%)
Number of PWD seen in Year 1	40	134 on database	74	54
Total grant awarded	630,000	700,000	700,000	700,000
<b>Consortium</b>				
Lead organisation	Primary care team	HSE Mental Health Services	HSE Services for Older People	Alzheimer Society
Lead contact	General practitioner	Consultant in Psychiatry of Old Age	Manager for Services for Older People	Regional Manager
Number of members	25	23	23	12
Management structure	Management committee of 6: 2 GPs (Kinsale PCT members), HSE OT manager Cork South, HSE Community worker Cork South, 1 carer 1 community member (an accountant)	Core management group of 6: 1 PWD 1 carer Project lead (Consultant in Psychiatry of Old Age) Deputy lead 2 representatives from the community	Management committee of 12  6 sub groups, each with lead person	Chairperson (Alzheimer Society), Vice-Chairman (HSE manager) Project manager Secretary (Mayo County Council) 1 family carer 3 HSE representatives 1 LEADER representative 1 fiscal agent 1 education rep



**TABLE 5.2** CONSORTIUM COMPOSITION

	Kinsale	South Tipperary	Stillorgan-Blackrock	Mayo
PWD		✓	✓	
Carer	✓	✓	✓	✓
Primary Care Team or GP	✓	✓	✓	
Consultant in Old Age Psychiatry	✓	✓	✓	✓
Consultant Geriatrician		✓	✓	
HSE Mental Health Services	✓	✓	✓	✓
HSE Community Care	✓	✓	✓	
HSE Occupational Therapy		✓	✓	
HSE PHN	✓	✓	✓	
HSE Other	✓	✓	✓	
Alzheimer Society	✓	✓	✓	✓
Educational institutes	✓			✓
Older people's groups	✓		✓	
Community groups – non older people	✓	✓	✓	✓
Community development organization		✓	✓	✓
Volunteer organization	✓	✓	✓	✓
Carers group	✓	✓	✓	✓
County Council			✓	✓
Other	✓		✓	

“ I LOVE  
COMING  
HERE ”

Person with dementia on his way to the K-CoRD café in Kinsale.

### Kinsale

The Kinsale Community Response to Dementia (K-CoRD) initiative is led by a general practitioner, Dr. Tony Foley. The latter is a member of a primary care team (PCT) with a strong interest in both dementia and education, which was well-placed to respond to the initial Genio call for expressions of interest in dementia. The project is currently organized under four working groups: individualized supports, education, community, and assistive technology. The project is driven from within the community. K-CoRD works in collaboration with the PCT and other agencies including Kinsale day care centre, the Alzheimer Society of Ireland and various community organizations, including the Kinsale College of Further Education, Cork Institute of Technology, University College Cork, and the Mercy Hospital Education Centre. K-CoRD is also a member of the Collaboration on Ageing (COLLAGE), which is the reference site for the European Innovation Partnership on Active Healthy Ageing (EIPAHA).

The initial consortium was recruited from within the PCT and the community of Kinsale and its environs. While there is no representative from the HSE management on the consortium, there is good communication and linkages between K-CoRD and senior HSE management. Serving a town with a rural hinterland with an estimated 250 people with dementia and 225 carers, the focus of the original proposal was on:

- Developing Kinsale as a dementia-friendly community, including raising awareness of dementia, recruiting a cohort of dementia volunteers, and developing a drop-in centre for PWD
- Providing individualised supports to meet the needs of people with dementia, their families and carers, including the provision of respite and day care
- Providing dementia education to healthcare professionals, volunteers and carers
- Exploring the use of assistive technology
- Conducting an audit of institutions with people with dementia

There have been some realignments since the initial grant was awarded. The use of external educators to facilitate inter-professional education was not pursued, as the costs were exorbitant and the skills and resources were available within the consortium. Instead, the project lead has bought out protected time to lead the education for health care professionals and training for health care assistants and family members. Initial plans to form a co-operative to employ health care assistants were also shelved. Instead, a decision was made to continue with external providers (Home Instead and Caremark) as the source for health care staff. Though external providers are

providing the employment structure for support workers, K-CoRD have sourced all workers to date, all of whom have completed the City and Guilds dementia module at Kinsale College of Further Education. The decision not to proceed with the development of a social enterprise to provide support workers was very much a pragmatic one, as roll out of supports had to be prioritized. Overall, however, the importance of having a local support panel that can respond flexibly to need through the individualized support plan was a key learning in the first year of the project.

The K-CoRD project is driven from within the community. According to the project lead, governance structures and relationships require significant time commitment to ensure that the project runs smoothly at consortium and management group levels. The main driver is the project lead, working with the leads of four working groups and the project manager. The four working groups are: individualised supports, education, community, and assistive technology. The process has to be managed carefully and occasionally there have been issues with multiple instructions to the project manager leading to the need to resolve resource allocation problems through agreed prioritization procedures.

Significant progress has been made in the first year in raising awareness of dementia, with community education evenings, a weekly K-CoRD Café and the training of 18 volunteers, with

Garda-vetting completed for 12 and underway for the remaining 6. The consortium organized a Dementia Care Conference attended by 200 health care professionals from a variety of public, private and voluntary agencies. The project has also received local and national press coverage and has a presence within various social media. An important initiative in terms of the dissemination about dementia has been the production of an ICGP reference guide on dementia for general practitioners that will be launched in Spring 2014.

Through K-CoRD's consultative process with the PWD, their carers, and service providers, K-CoRD is trying to encourage the appropriate provision of services and responses that need to be in place in the community at each stage of the illness. Individualised support plans are being drawn up based on appropriate packages of individualised supports. To date these include signposting, social support, the K-CoRD Café, innovative day care, assistive technologies and carer support and education. PWD well-being over time is being considered. Similarly, carer burden is being measured at baseline and over time. K-CoRD aspires to provide supportive packages of care that enable the PWD to live better in the community, as well as reducing carer burden.

K-CoRD is funding a part-time dementia care coordinator, who visits PWD and their families in their homes, assesses their needs and, through consultation,

offers the information, supports or services required, as well as providing ongoing support to the PWD. She also serves as the link with the K-CoRD clinical review panel, communicating clients' needs to that forum. The review panel meets every three weeks to plan and co-ordinate care needs for PWD. Two GPs, who link in turn with the four GP practices involved, a public health nurse, the care coordinator, the project manager and the day care centre coordinator sit on the K-CoRD clinical review panel. Referrals to the dementia care coordinator are made by families, the primary care team and general practitioners. The dementia care coordinator role is being extended from 1 day to 3 days per week in 2014. Support hours of 2-6 hours per week are being provided to 15 PWD by paid support workers.

Response time is now very low from the identification of need to the provision of appropriate services. A key element for the project leader in relation to individualized supports is that the latter should be an addition to HSE supports rather than a replacement for existing formal provision. In a period of rationing, there is always a danger that K-CoRD resources would be seen as substitute rather than complementary supports.

K-CoRD funds dementia-specific day care in a local day care centre one day per week and home respite care is provided by volunteers for 2 hours per week for 10 people. K-CoRD has also supported respite in Kinsale Community

case study

Mrs C, who has dementia, lives with her husband. Her three daughters, who all live locally, provide a rota of support. K-CoRD's Dementia Care Coordinator (Cathy) first visited her at home in March 2013. Support at home was offered but was declined. Cathy invited Mrs C to the K-CoRD café and other K-CoRD activities. She regularly attends K-CoRD social and VISION events with one of her daughters. Mrs C also attends the Kinsale Day Care Centre.

In June, family members told Cathy that they were contemplating long term care but declined individual support hours offered by Cathy. They were delighted though when Cathy organised that Mrs C could attend a second day at Kinsale Day Care Centre (K-CoRD supported day). Following reflection on how Mrs C had engaged with K-CoRD, the family made a request for formal support hours during Kinsale Arts Festival (KAF). This allowed her daughters to continue their involvement with KAF while also enabling Mrs C to attend some events.

Subsequently, K-CoRD's project manager discussed why support hours had been declined with one of the family. Shortly after this conversation, a support worker was matched with Mrs C and support hours are now in place including trips into town for a coffee where Mrs C may meet old friends and visit local art galleries.

*"It seems much easier the last six months."*

**MRS C'S DAUGHTER, DECEMBER 2013**

Hospital on two occasions. K-CoRD organises a range of other activities, including a monthly carer's group and a number of visual events as part of its VISION programme, which uses the arts as a means of engaging with people with dementia.

Soon after the start of the project, the need for a dementia register became apparent, leading to the two local GP practices developing dementia registers within their practices.

Significant progress has been made in the development of these dementia register and this has been a significant achievement in the first year of the project. The complexity and confidentiality issues around the developing of such registers are currently being reviewed. K-CoRD has also created its own register, which includes all those who have contacted K-CoRD themselves and, with their consent, those referred by their GP and public health nurse to K-CoRD.

Assistive technologies (AT) are being offered as part of K-CoRD's individualised supports package. With AT, only one in ten clients assessed were open to deploying the use of technology and K-CoRD have installed an Ambient Assistive Living (AAL) system in the homes of three clients, as a response to concerns about wandering. K-CoRD is working with the Centre for Affective Solutions for Ambient Living Awareness (CASALA) based in County Louth, both members of



COLLAGE, to explore the further use of assistive technology. It is hoped that the installation of a demonstration system in the K-CoRD Centre will encourage a greater deployment of assistive technologies, including stand-alone devices for lending to PWD and their carers. K-CoRD has worked closely with Cork Institute of Technology in relation to new technologies and has a student competition in this college year to develop an app for dementia.

### South Tipperary

The 5 Steps to Living Well With Dementia programme is led by Dr. Catriona Crowe, a Consultant in the Psychiatry of Old Age, working in the South Tipperary Mental Health Services. The catchment area is an urban/rural mix with an estimated 1,011 PWD and 1,250 carers. With an emphasis from the start on providing high quality, flexible, person-centred care in the home to help the PWD to stay living at home for as long as possible, the original proposal included plans to:

- Provide individualised home and community based support based on the needs of the person with dementia and their carer. It is person centred and activity focused with an emphasis on support, it is underpinned by the disability model of dementia.
- Deliver training and information to health professionals, dementia support workers, dementia volunteers, community

groups, people with dementia and carers.

- Raise community awareness of dementia through media and community involvement.
- Establish a single point of contact for the project for use by everyone with dementia and their carers.
- Provide dementia-related assistive technology, including an assistive technology library with a facility to trial appropriate technology. It includes stand alone items and telecare packages.
- Develop a research based tool to be used by people with dementia and their carers for end of life care planning.

The organizational form of the consortium is modelled on a consultant-led multi-disciplinary team. The key actors are the Psychiatry of Old Age team and the management group within that team. Most of the key players in the consortium were already working together prior to the Genio project, but the formal involvement of people with dementia and their carers as working partners is new, a feature very welcomed by all stakeholders. According to the project lead, a strong sense of social justice underpins much of the work of the group and building relationships was not difficult given the high level of trust that already existed.

With its origins in the Psychiatry of Old Age programme, there was already good experience within the team of working with people who belong simultaneously to two marginalised groups in society: the elderly and the mentally ill. The goal is to provide greater voice to people with dementia and ensure that pathways exist for them to navigate the system in a way that improves their quality of life.

Decisions on need and service provision are made within Psychiatry of Old Age team. The team always had a strong community-based orientation but can now deliver more in the community as a result of the Genio investment. The most significant progress in the first year of this project has been the sourcing of close to 20 dementia support workers (DSWs) who have already been trained up to FETAC Level 5, with recruitment continuing on an ongoing basis. They receive additional dementia-specific training from the consortium. The latter are employed by the Carer's Association (as is the project manager) and the Alzheimer Society of Ireland and provide practical and flexible supports for a fixed period of ten weeks initially. The number of hours provided per week is individualised and determined by the person's needs. The needs are reviewed when the 10 weeks are complete. So far, 132 people have received individualized supports from the consortium, with about 100 hours of support now being provided in an average week. The types of support provided by the DSW are many and varied, depending on the need and circumstances of the person

with dementia. For example, the DSW can take the PWD out into their own community in their cars if needed and provide support in maintaining connections and community activities. In many cases, the PWD can be reconnected to previous interests and also link with new activities.

One of the benefits of the individualised supports system is that once the need is identified, then the service can be provided immediately without any bureaucratic delays or multiple form-filling. The personalized support system is designed to meet the expressed needs of the service user and not around the needs of the provider.

A key benefit to the service user lies in the option demand provided by individualized supports, whereby people value the service for its existence should they need it at some time in the future, as much as its actual provision. A safety net now exists through this new matrix of care and this is becoming known and appreciated by potential service users and their families. There is a sense that for the first time in South Tipperary a community dementia team exists that is potentially available to all, with the capacity to respond flexibly to individual social needs as well as medical needs.

There has also been some reconfiguration of HSE expenditure as a result of the new consortium. Approximately €50,000 of HSE money has been reallocated to support four home help co-ordinators in the region,

resulting in additional home help hours now being available to people with dementia. Brokered by national HSE senior management, but linked very much to the Genio project, this initiative is very much focused on keeping people with dementia living at home with some people now receiving support three or four times a day, every day of the week. In one case a couple who both have dementia are getting that level of support – their only child living in the UK. The support of the HSE nationally has been invaluable, both in affirming the work of the consortium and in facilitating the release of HSE funds locally to support enhanced dementia care. The Psychiatry of Old Age team members have extended their community reach to all PWD, not just those with psychiatric complications, and their communities. They have a strong bio-psychosocial focus with enhancement of their educational role for PWD, their carers and the general community.

The consortium has made progress in creating a local identity for the project, through, for example, a dementia project logo and engagement with local media to publicise the project. They have also designed a lapel pin that is awarded to the DSW when the dementia-specific training is completed. That said the main concentration in the first year has been on getting the support workers in place and developing pathways to care, with plans for more focus on dementia awareness raising and public information during 2014. Work has

already begun in developing a dementia-friendly shopping centre as part of the process of raising awareness and making dementia more visible in day to day life.

Progress in regard to technology interventions is now accelerating: a second occupational therapist is being added to the team to deliver the assistive technology programme. Developments in this area have hitherto been somewhat unstructured with some uncertainty as to the most appropriate course of action, partly down to lack of knowledge of the technology sector and its potential benefits for people with dementia. However, ethical approval has now been sought for a telecare intervention and ten families have already been identified to participate in this initiative during 2014. Multiple assistive technology devices are available for lending or purchase from the consortium. PWD, family carers and public health nurses have all been involved in the selection of equipment for the assistive technology library. The absence of a room from the HSE to host the library has been the only constraint in developing this service further.

An interesting discussion taking place within the consortium is on the role of dementia advisors and particularly whether the role of advisors should be subsumed under existing providers, or whether new positions might be created. The main concern of the project leader in South Tipperary is to ensure that whoever delivers this service is qualified

to do so. This is, of course a debate that is likely to take place at national level in the coming months as well, with the imminent publication of the National Dementia Strategy. As well as the qualifications issue, there is the question of the embeddedness of dementia advisors within the existing health and social care system. For maximum effect, advisors would want to be able to influence both practice and policy within geographically defined areas.

The delivery of Home from Home support has not been pursued in 2013 and has been deferred for future consideration. Significant developments in relation to end of life care are scheduled for later in the project.

### Stillorgan-Blackrock

The Living Well with Dementia initiative in Stillorgan-Blackrock is led by Eilis Hession, the HSE Manager of Services for Older People in the region. Stillorgan-Blackrock has the highest national urban prevalence of dementia (1.19%) and approximately 15% of the population aged 65 or over. It is estimated that there are 500 PWD and 900 carers in the area. The focus of the original plan was to:

- Mobilise the local community, to raise awareness, and re-ignite old or develop new recreational and social activities for the PWD, providing innovative transport solutions to enable the PWD to travel to activities

John is a 73 year old gentleman and lives with his wife. They have two children who both live away from home. John has little awareness of his illness. His wife did not understand the illness and the associated changes it was bringing to their lives.

John began receiving 2 hours per week home-based support through the Genio project. It soon became apparent that this support was not sufficient.

Following lengthy discussion, his wife received individual education sessions. It helped her understand among other things why John can say *“it’s a lovely day”* 30 times in the space of 30 mins. John’s hours were increased to 3 hours per week, the equivalent of an afternoon off.

His wife was reassured that support was there for both herself and John.

*“The service is wonderful not only for John who enjoys the company of the support worker and getting out with him, but also for me.”*

### MARY, WIFE AND CARER

- Establish a dementia hub at the centre of the community as a focal point for information and activities
- Provide specialised dementia-care training for carers, volunteers, professional healthcare employees and the broader community
- Provide a range of respite supports shaped by wishes of PWD & their families/carers
- Facilitate the discharge of PWD from residential care to community where feasible
- Pilot a range of available assistive technology

Drawing on an existing strong volunteering ethos in the community and leveraging long-standing relationships among consortium members within the HSE, significant progress has been made across the board in the first year of the project, although like all projects progress has been stronger in some areas than others. Two objectives from the original expression of interest have been removed:

- The introduction of a daffodil nurse to support the PWD to die at home - this service was introduced by the Irish Hospice Foundation with funding from Atlantic Philanthropies
- The support of PWD in acute care settings - agreement was reached with the Genio programme that this is beyond the realistic scope and time frame of the project

In line with other sites, it is not surprising that some areas are given higher priority than others in the first year of operation. Given limited time and scarce resources, choices have to be made.

The project lead is the Manager of Services for Older People in HSE Dun Laoghaire. She has an ongoing strong working relationships with colleagues within the Primary Care teams, Medicine of the Elderly and the Department of Old Age Psychiatry - HSE Dublin South East/St. Vincents University Hospital, HSE grant-aided organizations including NGO's, Voluntary & Community Groups and other Statutory organizations within the area. She is Chair of the Local Placement Forum and has contact with a wider network of older persons organisations through the Dun Laoghaire Rathdown (DLR) East Garda Older Persons Consultative Committee and the Older Persons Service Providers

Forum, a combined initiative of the HSE and the DLR County Council. These relationships maximize the interconnectedness of the consortium in relation to placement decision-making, stakeholder organisations and PWD. The project lead has strong contact and support from colleagues within the PCT, which has allowed the project to profit from the existing healthcare support structures, ensuring continuity of care for people referred to the project.

The project is hosted by Southside Partnership, which has allowed the consortium to benefit from existing finance and administration supports. Community employment (CE) and TUS (community work place initiative) staff were sourced through Southside Partnership to provide administrative and community support services to the consortium.

**case study**

*“ It is absolutely magical to hear my dad sing. It has showed me a new side to my dad and given us a whole new relationship.*

*When caring for someone with dementia, it can be very difficult. Sometimes you feel like you are giving and giving, putting a lot in and not getting a lot back. This choir is the one time in the week when I get something back from my father. And wow do I get back!*

*It is incredibly rewarding to see him enjoying himself, being his old sociable self, making jokes and singing harmonies and being creative; it's like his dementia just disappears in this group. I have seen a massive transformation in him from the start of the project until now.”*

**FAMILY CARER**

*“John is aware of some of the negative effects on him of his particular dementia. As we have developed an easy relationship he feels free to talk about these as we walk. John is significantly fitter than I am, so our joint ventures have had a hugely positive effect on me, and I make sure he is aware of this.*

*We started our walks in one of the local parks. So as to “sign up” to continuing our mutual befriending project we got a list of all the DLRCoCo public parks and began to walk them all.*

*John has great eyesight and we have found great fun observing the antics of the squirrels, birds and fish he has spotted. My hobbies include woodwork so I have tried to help out by noting tree species.*

*John and his wife assure me of the benefit he gains from our regular outings. I have certainly gained a great deal: having become fitter than I would expect at my age; having become more attuned to nature; having gained a good friend; having gained an informed insight into some of the effects just one stage and form of a condition close to many thousands in our area.”*

**VOLUNTEER BEFRIENDER**

This allowed the project manager to focus on delivering the actual supports rather than having to develop and install new bureaucratic structures. The project has also connected with other services under the Partnership, e.g. co-ordination of volunteers, use of training network, Care and Repair services. The project manager reports to the project lead on a daily basis, with a management team drawn from a number of different organisations that meets monthly. Different leaders have evolved to drive various aspects of the project drawing on their

experience and strengths, for example, assistive technology initiatives are led by an occupational therapist on the management team. A wider consortium representing 20 different organisations meet quarterly.

The addition to the care landscape directly attributable to the Genio programme has been chiefly in the area of flexible, person-centred home supports, which have been tailored to meet the needs of the PWD and their family carers particularly in relation to respite care, social activities and social

participation. From the beginning, the project has offered support based on actual need. Up to 20 people have been provided with flexible in-home, person-centred supports ranging from 3 hrs per week (to allow a male spouse who has taken over cooking to attend a cookery class) to a planned block of weekend support (to allow a person travel to a family event). Emergency in-home support has also been facilitated where extreme carer stress was identified as requiring an immediate response by a key support worker.



As a consequence, family carers have been able to take breaks from caring, admission to long-stay may be less likely (and in some cases actually deferred), and a small number of people have been able to return home from acute care settings for palliative care, allowing three PWD who expressed a wish to do so to die at home over the past year. In another case, pre-planned scheduled home care, including intensive support from a physiotherapist, was provided to one PWD after a hip replacement, allowing the PWD to return home and live independently and actively engaging in life.

Emergency in-home support has also been possible in crisis situations. Although the number of people receiving various types of respite care is still small, the option that respite care is available in a crisis situation arise should not be under-estimated, with family carers valuing the fact that targeted respite care is now available should they ever need the service in the future. It should also be noted that a number of people involved in the project are also supported by generic HSE person-centered flexible Home Care packages.

Based on an expressed need by PWD and their family carers, two respite supports have been successfully launched. Musical Memories Choirs, in partnership with DLR County Council Arts and Health Partnership, and the Tuesday Activity groups respond to a range of needs, offering peer-to-

peer support for both the PWD and carers, cognitive stimulation, mental health support (through music and exercise), social interaction and physical exercise. Located in the community, these support groups provide for a normalisation of dementia, and are supported by intergenerational volunteers. Both activities are led by trained professionals: a physical therapist from Siel Bleu<sup>1</sup> delivers the Tuesday Activity group, and a choral director with recognised experience in the support of people with learning disabilities runs the choirs. Part of the contract with Siel Bleu and the choral director is the evaluation of the physical and social progress of each participant, which in turn is provided as feedback to key-workers and family members. Participation in these support groups by PWD have led to other valuable connections and projects: for example, a couple from the Tuesday Activity group now attend a dance class run by Siel Bleu.

A team of 16 volunteers have been built up to support various activities and also for befriending purposes. Friendships have been nurtured through music, walking, golf and just chatting. There is direct evidence from families that the volunteers have made a significant contribution to the well-being of people with dementia with whom they have

been in contact. There has also been some success in mainstreaming social activity for people with dementia through embedding them within existing generic groups, for example walking groups and a golf club. The role of Southside Partnership is critical in ensuring the development and sustainability of the pool of dementia volunteers in the area.

The consortium has hosted six evening family carer events to date reaching over 90 families. These events have provided an opportunity for families to gain knowledge, share experience and build support networks and have additionally, a strong educational component for both families and health-care professionals. The venue was donated by a local school and the event run by a team of health care volunteers.

One-on-one drop-in support for family carers is available monthly provided by health care professional in a community location. This is open to all community members, not just people with a diagnosis of dementia and not just those living within the Stillorgan-Blackrock area. In 2014, there will be a six-week programme of training for family carers serving up to 20 families. Some elements will be delivered by external providers and others by staff within the HSE. St John of Gods Hospital has donated a venue for this activity.

There has been a significant increase in shared learning, communication and cooperation among the different

<sup>1</sup> Siel Bleu is a non-profit organisation who promote appropriate physical activity for those that wish to maintain or increase their physical and mental health.

health-care disciplines in the Stillorgan-Blackrock area. This has resulted in better health-care planning for the person with dementia. A number of people have been identified and referred to the project for support to stay at home and a personalized plan drawn up identifying the areas where the Genio project can provide support. The Department of Old Age Psychiatry at St Vincents Hospital and members of the PCT have participated in six individualised support meetings, sharing knowledge and gaining a better understanding of the role of each group.

Assistive technology has been slow to progress, mainly, according to the project lead, because people prefer human interaction. The process for the roll-out of assistive technology (ethics, consent, monitoring, and evaluation) has taken considerable effort and continues to take time to get right. In addition to telecare training for the PCT, telecare was presented at a family carer event and emergency response telecare installed with a small number of families, monitored by the ASI. Plans are now well advanced to identify people for an assessment for telecare by an OT. The development of a dementia-friendly community per se has also been slow to formulate. However, the large community support in terms of provision of venues and volunteers has indicated that considerable support exists for such an initiative during 2014. This will be a major focus of activity in 2014.

## Mayo

The Community Action on Dementia in Mayo programme is led by Des Mulligan, a Regional Manager with the Alzheimer Society of Ireland (ASI). The area served by this programme is a dispersed rural area with a population of 130,000. The main focus in Mayo is on encouraging early diagnosis and early intervention, in addition to developing Mayo as a dementia-friendly community and having individualized supports available to people with dementia. The main elements of the original plan were:

- To create better awareness and understanding of dementia in the general public
- To facilitate the person with dementia in maintaining their social network and recreational activities following diagnosis
- To work with the person with dementia and their family following diagnosis in preparing for and planning their future needs
- To maintain the person with dementia within their community through innovative alternatives to traditional respite care, and the use of assistive technology

There has been some subsequent realignment of objectives. Home from Home and Boarding Out respite care were not pursued and the money initially allocated for these two activities are now going into the individualised

supports budget. The reasons for the change in plans were lack of time and management expertise to pursue either option, allied to fears that these options were more risky and therefore likely to be associated with heavy regulation.

The project leader reported that the consortium came together very easily with great enthusiasm at the outset, particularly in regard to the mobile screening objective. The project is firmly based on a primary care community-based model, although the absence of a general practitioner from the consortium is noteworthy given the primary care orientation. It is the only project where the lead is outside the conventional clinical, medical or HSE framework, based as he is in the Alzheimer Society of Ireland. Consequently, there is a strong focus on the psychosocial model of provision and social supports for people with dementia within a community development framework.

The theory behind the consortium was that there would be shared responsibility for the delivery of objectives, but, unfortunately, the reality has proven to be somewhat different. A parallel service has now developed from the work of the consortium that is both enlightened and person-centred in orientation, but one that is outside mainstream provision and is not embedded in existing clinical, medical or HSE practices or structures. Currently, the project lead and project manager are driving the project, which is linked to local development groups, such as Leader

## case study

Mrs X is a 62 year old widow with a diagnosis of vascular dementia, living alone in a rural setting. Her only son lives in Dublin. Following a fall in early 2013 she had steadily deteriorated and her GP no longer deemed her able to drive, which caused Mrs X to become withdrawn and requiring her son to visit more often.

Her son contacted the Genio project manager to ascertain if we could provide a service.

On meeting Mrs X, she came across as a lively character, able bodied, with some insight into her memory difficulties and was willing to speak about it. She explained *“I can no longer hop into my car and go wherever I fancied, I miss my freedom’*. Her interests prior to diagnosis were meeting with former work colleagues, socialising and attending musical events in local towns.

In consultation with Mrs. X, individualised support is now in place, with a support worker collecting her three days a week: one day, agreeing with her a location for a walk, from a short-list previously identified by Mrs X; once for an evening of social dancing or to meet her former colleagues for a chat; on Fridays, to have her hair done, do her weekly shopping and to visit a family relative, a weekly routine prior to diagnosis.

and LDSIP, but without much support from health and social care providers within the formal care system. There is significant work going on in relation to the mapping of needs and services, but in the absence of shared responsibility and shared leadership with existing service providers progress is likely to be truncated and potentially unsustainable.

The most significant achievement in the first year has been the development of a dementia-specific team in the community. The focus of that team is on developing local strategies around timely diagnosis, post diagnostic support and early intervention within the persons own community. In addition to the project manager for the programme, a Dementia Advisor, a Memory Assessment Coordinator and an Early Activities Coordinator are in place, three part-time posts. The Dementia Advisor is located in the Ballina primary care centre and runs outreach clinics in three locations. Referrals come from many different sources, including the project manager, the memory assessment coordinator, the ASI, GPs and PHNs. The Dementia Advisor provides one-to-one consultations with PWD and/or carers (89 in the first year) and provides emotional support and information on services that are available.

The Memory Assessment Clinic is also based in the Ballina primary care centre with two outreach locations that has seen 136 clients assessed to date. In the absence of a dementia register, this is a



THE MOST SIGNIFICANT ACHIEVEMENT IN THE FIRST YEAR HAS BEEN THE DEVELOPMENT OF A DEMENTIA-SPECIFIC TEAM IN THE COMMUNITY. THE FOCUS OF THAT TEAM IS ON DEVELOPING LOCAL STRATEGIES AROUND TIMELY DIAGNOSIS, POST DIAGNOSTIC SUPPORT AND EARLY INTERVENTION WITHIN THE PERSONS OWN COMMUNITY.



significant achievement given the zero baseline at the start of the project and should not be under-estimated.

The person assessed at the clinic has the choice over whether the results are sent back to their GP; to date six clients have subsequently been given a formal diagnosis by a GP or a geriatrician following assessment at the clinic. Initially, those referred to the clinic tended to have more severe dementia (average MMSE scores were low), but as public awareness of the clinic grew, those with milder dementia have increasingly been drawn to the service (with MMSE scores in 17-20 range).

The role of general practitioners is important in terms of referrals to the clinic and subsequently in referring people with dementia upstream to specialist services. However, there is currently a gap in knowledge and engagement by GPs in the project, which the consortium is attempting to bridge through improved information flows and an upcoming master class in dementia delivered by a GP project leader from another consortium. That said, more referrals to the clinic are now coming from GPs than at the beginning of the project. Ideally, the clinic should

facilitate over time the development of a dementia register at primary care level.

The Early Activities Coordinator is located at the ASI in Castlebar and is in contact with 59 clients. She is currently working with 9 clients to provide individualized supports to help them maintain as close to a normal life as possible, whether that is to manage their farming activities, to attend cultural events or to continue to pursue a past-time. Individualised supports are provided by six staff employed by the Carer's Association; it is envisaged that volunteers will play a bigger role in providing individualized supports in the future with sixty three people now going through Garda vetting. The PWD (and their families) are encouraged to take ownership for defining the supports that should be provided to them, with an emphasis on health promotion and health maintenance and delaying having to access formal care services for as long as possible. Mayo has a particular emphasis on person-centred provision, where the PWD has a strong voice in how scarce resources are allocated. The concern is that there is not enough emphasis on the integration of formal and informal provision and an

embedded approach to service delivery involving all stakeholders, formal and informal. This is difficult to achieve, as dementia is not formally coordinated in Mayo, making it difficult to determine where integration should begin and end.

Significant progress has been made in developing dementia awareness in Mayo, which has led to the greater knowledge about dementia and the existence of the screening clinic, as well as engagement by more community groups wanting to join the project. Appointments for screening are now occurring naturally and much less effort is required to fill schedules than in the early weeks of the service. A recruitment campaign in the summer months attracted a significant number of volunteers to the project. Dementia awareness and training sessions have been delivered throughout the year to support workers under the EAC scheme and to TUS and CE participants, as well as to community organisations in three locations in County Mayo. An Alzheimer's Café was launched in Ballyhaunis in September. The consortium has advised an Age-Friendly Town initiative in Foxford on how to make businesses and the town dementia-friendly, as well as age-friendly.





# 6

## Key Learnings and Outcomes

**A MAJOR** objective of this report is to distil important learnings from the first full year of operation of the Genio dementia sites set against key outcomes as specified by the funders of the project. Our analysis therefore is particularly focused on the impact of this investment over the past year in relation to the public awareness of dementia, diagnosis, community-based supports, integrated provision and sustainability. It is not possible at this stage to determine if fewer people with dementia are being admitted to residential care as a result of the four projects, but it is possible to comment on many aspects of care and provision that would lead one to conclude that the quality of life for people with dementia and their carers has improved. Similarly, it is possible to identify whether services are being delivered in a more collaborative and integrated manner with enhanced awareness and skills. This section is organized, therefore, around the key generic themes that formed the basis for the submissions made by the four sites and the allocations that followed the award of the grants.

### Public Awareness

The four sites have made good inroads into raising awareness of dementia among the general public. All four sites used formal launches of the Genio programme covered by local media as an initial initiative to raise awareness of dementia. The

organisations in the consortia publicised their Genio programmes on their own web sites and in newsletters and other communications with their members. It is worth noting that dementia would not automatically be on the agenda within many of the organisations making up the consortia groups for example, community development groups, County Councils, and arts and sports organisations. In Stillorgan-Blackrock, an awareness session was held for all members of the consortium, covering Community Development, Understanding Dementia and the Dementia Champions.

Public information events were held in all four sites, as community information evenings or targeted at specific organisations. The consortium at times partnered with other initiatives to increase awareness of dementia, for example, Mayo contributed to a workshop organized for the Foxford area by the Age-Friendly Network, providing hints and tips to local businesses how to become dementia aware and dementia friendly. In Kinsale, K-CoRD used Bealtaine, Positive Ageing Week and the Kinsale Arts Festival to raise awareness and promote the programme. Dementia training programmes delivered as part of Genio also help raise awareness of dementia, as many participants would not otherwise have access to this training, for example, TUS and CE employees, volunteers recruited for Genio and transition year students.

The visible presence of the Genio programme in each area is also helping to raise awareness: the dementia Café's in Kinsale and Mayo, the programme logos developed at each site and used in all communications, and a specially-designed lapel pin presented to dementia support workers on completion of training in South Tipperary. A heightened focus on dementia has been generated among the PCTs involved in the consortia in Kinsale and Stillorgan-Blackrock. Drafting the reference guide on dementia for GPs, which is due to be published in Spring 2014 and included in the National Continuing Medical Education for GPs is a significant step in raising the focus on dementia among GPs nationwide.

### Diagnosis

Different approaches have been taken to help improve the complexities around receiving a diagnosis. In Stillorgan-Blackrock only those with a diagnosis of dementia are admitted into the programme for paid respite, although other support activities are open to a much wider group, for example, the choirs, which are open to all older people but specifically welcome PWD. Similarly, in South Tipperary, diagnosis is less problematic given the locus of the project within Old Age Psychiatry and the support of the memory clinic in the area. Post-diagnostic support groups have also been set up as part of the Genio programme.

“ THE DEMENTIA SUPPORT WORKER IS SOMEONE ELSE IN HIS LIFE, HE IS ANIMATED ON RETURN AND FULL OF STORIES ABOUT THEIR TIME OUT. ”

Family carer, South Tipperary

In both Kinsale and Mayo, the absence of a dementia register was noted by the consortium early in the programme. The Memory Assessment Clinic in Mayo is a major element of their programme and has assessed a significant number of clients to date, but only a small number of these have subsequently received a formal diagnosis, mainly due to weak interaction with the formal health care system and poorly integrated dementia care within the county. Two local GP practices in Kinsale have developed dementia registers within their own practices, while the K-CoRD register includes all those who have contacted or have been referred to K-CoRD, provided the PWD or their carer consents to inclusion on the register. Both Mayo and K-CoRD consortia believe that it is essential to have a dementia register to allow the development of an adequate response in primary care.

### Community-based supports

Somewhat different approaches have been taken in the four sites in how individualized person-centred, community-based supports are provided to PWD and their families/carers that enable them to live longer within, and to

integrate and be more visible in, their local community. But there is a lot of similarity in the nature of the supports provided:

- **Support workers**, trained in dementia care by the Consortia, providing in-home support to the PWD, ensuring a family carer can take a break for leisure time or to attend a medical appointment or spend time with other family members. In-home support is provided through the Genio initiatives in all four sites on a regular weekly basis, typically for 2 or 3 hours per week per person, although in both South Tipperary and Stillorgan/Blackrock, home support is provided to some PWD a number of times each day, up to 7 days a week. It is also provided for specific events, for example, to allow a carer go to a wedding, and is available on a crisis basis in some sites.
- **Support workers and volunteers** offer flexible and practical support to PWD, enabling the latter to continue to take part in community events and keep connected to friends and neighbours. Examples include visits to the Alzheimer’s Café in Mayo, attendance at the K-CoRD social café

in Kinsale, and taking part in the choir in Stillorgan/Blackrock. In the latter site one PWD has re-connected with the local walking group, another with his golf club. Without such support, social connections would be much less for PWD.

- **Activities specifically developed for PWD** as part of the Genio programme, including choirs and activity groups in Stillorgan, Alzheimer’s Café (Mayo) and dementia-specific day care in Kinsale. Family members or volunteers accompany the PWD to these events.
- **Use of telecare and assistive technology** to enable PWD remain at home. By its very nature, the development and adaptation of new technologies was always likely to be lag behind other interventions across all sites. Understanding need, want and demand in relation to new technology is a slow process and requires careful understanding of the caring circumstances of potential recipients and their ability to engage with new devices. On the demand side, presentations and representations have been made to

PWD and families about the type of assistive technology that is available, but to date uptake has been slow across all sites. Not surprisingly, given the weakness of demand, and uncertainty as to the merits of various technologies, none of the sites have prioritised technological innovation in the first year of the programme. There is, however, activity to report across all sites. In Stillorgan/Blackrock, emergency response telecare has been installed with four families, monitored by the ASI. Ambient Assisted Living (AAL) systems have also been placed in three homes in Kinsale. In South Tipperary, significant progress has been made in identifying PWD for whom telecare support is appropriate and in identifying suitable products, in consultation with PWD and their carers.

- **Overnight respite care** is available in three sites. In Kinsale, overnight respite care is occasionally provided

overnight respite is also provided and in Stillorgan/Blackrock both overnight and weekend respite has been facilitated, where PWD and/or carers have opted for out-of-home respite, although in-home respite is also offered.

- **Provision of information to PWD and the family** – for people in the early stages of dementia. Providing information on dementia, particularly on the various supports available, including introducing the family to Carer Support Groups, has been a major source of activity in all of the sites. The provision of information is critical to establishing baseline parameters for the development of person centred care and holistic pathways to care as the disease progresses. Information is a key ingredient in establishing equilibrium and an appropriate balance of power in the relationship between the recipients of care and the providers of care. When there is an information

people with dementia may not get what they want if they are unable to articulate their needs due to poor information.

- **Discharge home** from a nursing home or acute hospital is only available on a very small scale, but there are encouraging signs that all sites see this as an important part of their remit. All sites are gearing towards the development of individualized plans incorporating in-home support, assistive technology and planned links with local services, for example, Meals on Wheels, to allow PWD to return to his/her own home following an admission to acute care or nursing home setting. By having close contact with the Genio programme and developing an individualized support plan, there has been some already some success in individual cases in relation to discharge from nursing homes (South Tipperary), delaying entry to

“ THE CHOIR IS NOW BUILT INTO MY WEEK, I REALLY WOULDN'T MISS IT FOR THE WORLD. ”

Person with dementia, Stillorgan/Blackrock

when all HSE support has been exhausted, either in the local community hospital or by a support worker staying overnight in the home of the PWD. In South Tipperary,

asymmetry in the relationship between people with dementia and their formal care providers, in favour of the latter, it is unlikely that care provision will be optimal. In practice,

long-stay care or allowing a PWD who required palliative care to return home from an acute setting to die (Stillorgan-Blackrock).

## Integrated Care

The individualized supports are being planned, organised, and integrated in different ways across the four sites. Identifying PWD who might benefit from individualized supports and information on their needs are brought to the decision makers in different ways: in Kinsale, the Dementia Care Coordinator gathers information through contacts with the PWD and family members while in South Tipperary clients are already known to the Psychiatry of Old Age team. The highest level of integration is evident in Stillorgan-Blackrock, where the project manager is embedded in existing HSE provision, GPs are part of the consortium and the Department of Old Age Psychiatry at St Vincents hospital identify PWD and their needs. The greatest difficulty in identifying PWD has been encountered in Mayo.

In the absence of a dementia register and with little involvement of GPs in the Genio programme across the county, the personnel in the new posts funded by the Genio Dementia programme have had to work very hard to source, one by one, people in need of individualized support.

Decisions are made on the provision of individualized supports in different ways. In Kinsale, decisions are made at regular K-CoRD clinical review meetings; in Mayo, by the dementia team, consisting of the project manager, Dementia Advisor, Memory Assessment Coordinator and the Early Activity Coordinator. In South Tipperary decisions are made from within the Psychiatry of Old Age team. Decision-making in Stillorgan-Blackrock is more devolved, relying on consortium members within the HSE

to make most decisions on the nature of the individualized supports following consultation with appropriate medical and clinical referral teams.

The key worker for dementia in each site has different titles (project manager/dementia advisor/dementia care coordinator/project coordinator) and there are some differences in their job specifications, but all of the evidence points to the importance of this coordinating position in the overall process of providing individualized, person-centred support to the PWD. The dementia champion puts the building blocks in place in the community in terms of paid carers and volunteers to organize and deliver the agreed supports. Ongoing feedback to these people on the ground, from the PWD, family members and from the support workers is key to ensuring



BEING A MEMBER OF THE CONSORTIUM AND WORKING WITH LWwD HAS INCREASED MY KNOWLEDGE AND ENRICHED MY WAY OF WORKING WITH A PWD AND THEIR FAMILY. NOW IF REQUIRED I CAN CALL, FOR EXAMPLE, A MEMBER OF THE PSY OF OLD AGE TEAM AND DISCUSS THE MANAGEMENT OF A PWD AND ACTION IT DIRECTLY FOR THE PERSON / FAMILY MEMBER. PRIOR TO LWwD, I JUST HAD NAMES BUT WE DID NOT HAVE THE WORKING RELATIONSHIP/ COMMUNICATION BETWEEN THE DIFFERENT TEAMS WHO ARE INVOLVED WITH THE PWD. THIS IS CONTRIBUTING GREATLY TO A PWD.



GP, Stillorgan/Blackrock

that the supports evolve with changing needs. Being located in the community sector is a key contributor to the success of this role, helped by the ethos of a community organization, the pre-existing connections with other community/ voluntary organisations, the local knowledge and the pre-existing communication between the public and the organization. The question still remains, however, whether there is a need for a new post of dementia champion, or whether existing care personnel should take over their functions as a part of their normal job. This question, while very important, will not be answered in this report.

In all four sites, the Genio programme draws on the existing strengths of community groups, mainly consortium members but some from outside the consortia. For example, the Southside partnership in Stillorgan/Blackrock is responsible for recruitment and management of volunteers and is home for the Genio volunteer coordinator. The Partnership has extensive experience in community development, protection of vulnerable people and information and training. In South Tipperary, the Dementia Support Workers were accessed through the Alzheimer Society and the Carer's Association and dementia-specific training delivered by the consortium. In Kinsale, the Genio programme funds additional health care assistants for the dementia-specific day at the local day care centre, but the

service is delivered using the facilities and expertise of the community day care centre. Volunteer training in Kinsale is delivered in collaboration with the Alzheimer Society of Ireland, while K-CoRD itself delivers community education on dementia. Some individualized support plans involved interaction with organisations outside the consortium, for example, the Garda Síochána and Meals on Wheels. The strategy of drawing on the existing strengths of organisations minimizes the duplication of effort and ensures that no time or money is wasted.

In all four sites, there is evidence that community care organizations, psychiatry teams, acute hospitals, public health nurses, primary care teams, families, volunteer organisations and mainstream organisations (not dementia-specific) are working together to deliver integrated care along a continuum from strong to weak. Engaging with mainstream organisations is a critical component, as it moves discussions on dementia into parts of society where it may not usually happen, for example, sports clubs and cultural organisations. However, engagement with community-based organization is varied across sites and has not always proven to be easy for a variety of reasons. For example, partnership with the local GAA club in Stillorgan-Blackrock could be better, as could partnership with Muintir na Tire in South Tipperary.

“ THE CONVERSATION ABOUT DEMENTIA IS NOW TAKING PLACE INTERNALLY IN ORGANISATIONS WHERE IT NEVER WOULD HAVE BEFORE. ”

Consortium member, Mayo, on the benefits of integrated working through the consortia.







# Sustainability

**A CONSORTIUM** with a large number of members, drawn from as wide a base as possible, is a good starting point for sustainability, but it must be driven by a tight, committed management team, with other consortium members clearly aligned to specific sub-committees/groups. Given that the HSE are the dominant partner in managing funding for and delivering services to older people, it is important that at least one HSE representative is an active member of the management committee, if not the chairperson/lead person. This structure could then become a sustainable framework that could continue on in the various sites after the end of this project and could potentially be rolled out nationally. For example, the consortium in Stillorgan-Blackrock is embedded within the HSE and builds on pre-existing relationships between the project leader and both the formal care sector (Primary Care Team, HSE Medicine of Elderly, HSE Department of Old Age Psychiatry) and community organisations (NGOs, voluntary and community organisations) and other statutory organisations. The involvement of the Southside Partnership as hosts to the project also draws on existing structures/expertise, for example, co-ordination of volunteers and use of a training network, and recruitment of CE and TUS staff. The project manager had also worked as a project manager in a voluntary befriending service for older people in DLR since 2009 and had strong community connections and

commitment. In South Tipperary, the consortium was built primarily on existing relationships, where a high level of trust already existed between the Psychiatry of Old Age team, geriatricians, public health nurses, GPs and the Advanced Nurse Practitioner in dementia.

The consortium in Mayo is based on a community-based model, linked to local development groups (e.g. LEADER and carers groups). It is the only site where the lead person is not located within the HSE framework or attached to a PCT. It has the clearest vision of person-centred care of all the sites and much effort is expended on keeping people with dementia away from the formal system, thereby reducing the possibility of structured dependency occurring. However, while there was initial enthusiasm for the consortium, active involvement of members has varied and the original plan for shared leadership between all key players has not materialized in reality. Although dementia is now on the agenda in organisations in Mayo where it would never previously have been discussed, key decision makers have not engaged with the project sufficiently to allow a holistic care model to fully emerge. The project lead has identified this issue and plans are in place to address it in 2014. The consortium in Kinsale is located very much within the community, while making a major difference in the primary care arena. However, it is also important that the HSE makes a stronger

contribution to the consortium in this site, thereby ensuring that integrated care becomes a reality.

All four sites are driven by a strong desire to make a success of the programme and have worked exceptionally hard to realize their ambitions. But they must also be realistic in regard to what can be achieved in such a short time and against the background of a fragmented response to the delivery of care for many people with dementia across the country. The time commitment and personal dedication of consortium members to make the Genio programme work cannot be over-emphasised. For many people, working on the Genio programme is an addition to their normal workload. Monthly management meetings, quarterly consortium meetings and regular sub-committee meetings are usually held outside of normal working hours. In particular, the project leaders involved in the consortia have a major additional workload. The reality is that it takes time to plan and deliver change and then even longer for change to be accepted. This should be taken into consideration if and when roll-out in other regions/sites is being planned.

The organisation of the management team is also critical, particularly in regard to the devolution of functions and responsibilities. Following the principle of subsidiarity, responsibility should lie with an individual with

decision-making capability in that field. The structure in Stillorgan-Blackrock is a good example: a sub-project focusing on referral pathways is led from within the HSE Department of Old Age Psychiatry, assistive technology is led by an occupational therapist, while responsibility for volunteer management is located within the Southside Partnership. In sites where responsibility is not clearly defined, or vested only in one individual, progress is likely to be slower.

There seems to have been a steep learning curve in every site, and a reluctance to commit resources initially, and that was in circumstances where advice and support was available from Genio. This reflects an absence of an integrated and holistic approach to health and social care in the Irish system generally, which makes it very difficult to develop such an approach from first principles. This is new and novel in the context of health and social care provision for older people in Ireland, where not only are resources scarce but often poorly coordinated even when they are available. Genio and the four sites reported on here are at the forefront of a major cultural change in respect of dementia care and project leaders are being asked to make significant progress in a system that has resisted change up to now. In the circumstances, performance across all sites has been very good, but more support may be needed on the change

management aspect of the work, particularly in relation to the articulation of key objectives and the interface between the projects and resource allocation decision-making in the HSE. Only in South Tipperary, for example, has any realignment of public resources taken place within the sites.

More work is also required to encourage priority-setting within each of the four sites. Not everything can be done and not everything will be successful so choices have to be made on where best to allocate scarce resources. This means making decisions, for example, on whether it is better to focus attention and spending on people with dementia on the margins of residential care rather than those in the early stages of the disease. Similarly, is it more rational and effective to provide many hours of individualized supports to just a few people with high levels of need, or very few hours of support to a great many people with low levels of need? Similarly, should resources be concentrated on those who live on their own without any support from family or friends rather than on those with strong family supports? Concentrating resources on those in greatest need or who are most vulnerable can yield higher overall benefits, particularly when it comes to delaying admission to residential care. It was not easy to get a clear sense of how rationing decisions were made in the various sites and whether serendipity sometimes played a

role in who gets what, when and where. It was not always obvious from the outside even how people with dementia were selected for inclusion in the Genio dementia programme in the four areas.

It is not clear that enough has been done to draw on experiences in other arenas. Stillorgan-Blackrock said they would use experience of Headstrong (Youth Mental Health) and it is not clear if this has happened or to what extent. Mayo references the Mayo Intercultural Action (MIA) organisation, but again there is no strong evidence of a major contribution from this source, which might have been interesting given the focus on human rights. Kinsale seems to be meeting the needs and visions of the PCT, but are there enough influences from outside this sphere on different ways of thinking about dementia care, particularly in regard to psychosocial interventions? Similarly, South Tipperary is heavily influenced by Psychiatry of Old Age, but it would be interesting to see other influences at work here, particularly from the community development sphere.

More generally, the social model of disability contains many lessons for dementia in relation to person-centred care and empowerment, but also in terms of information, advocacy and policy formulation. The links to the disability movement in all sites is tenuous and strengthening the relationship between dementia and

disability can yield significant gains over the next year. So too can more sustained attention on personhood within dementia. Most of the sites have concentrated their efforts on doing things for people with dementia, for example getting more individualized supports into homes, but there is much to be gained from allowing people with dementia to speak more for themselves and to have the space and time to do this. By paying more attention to how personhood and well-

Dublin explored supporting family carers to become self-employers, receiving funding to allow the family (and, in the early stages, the PWD) to select and manage a non-family carer. While it is not clear that the current legislative environment supports this option, more experimentation with payment systems could yield valuable information for policy-makers. Mayo planned initially to develop alternative community-based respite models but dropped both Home from Home (mainly a day care service

new ideas prove not to be worthwhile. This issue needs to be addressed further by Genio and reassurance provided that sometimes progress is not linear and that the learnings from new ideas that fail are as important as any successes.

Finally, throughout the first year, each consortium gave some consideration to ensuring that the work of the Genio programme would continue beyond the life of the programme. The benefit of the education and training programmes delivered will last in the community; in sites where new educational resources have been developed for Genio (e.g. Kinsale), those resources will continue to be made available and, in some cases, train-the-trainer programmes will ensure the capacity to continue to educate new participants in the future. Significant knowledge on dementia, on the services available, on desirable services, about delivering integrated care and about creating links across communities has already built up over a year within participating organizations. This knowledge will widen and deepen over the life of the Genio programme and will remain in communities long after the end of the funding. Even after one year, it is clear that serious capacity building is underway in each site, and this capacity will be available to further develop integrated care solutions in those areas, but can also be shared with other areas who may value the opportunity to implement similar solutions.

“ GENIO AND THE FOUR SITES REPORTED ON HERE ARE AT THE FOREFRONT OF A MAJOR CULTURAL CHANGE IN RESPECT OF DEMENTIA CARE AND PROJECT LEADERS ARE BEING ASKED TO MAKE SIGNIFICANT PROGRESS IN A SYSTEM THAT HAS RESISTED CHANGE UP TO NOW. ”

being are enhanced through their direct engagement with people with dementia, sites can be much more persuasive when explaining how their model of care is different to the conventional approaches to the care of people with dementia in Ireland. As a starting point, each site would benefit from having people with dementia much more visible within their consortium and much more involved in decision-making.

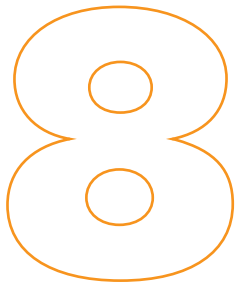
Another consideration is whether the sites have engaged enough in innovation and experimentation. South

in a local house, with some provision for emergency overnight stays) and boarding out (overnight accommodation for 1 to 7 nights, with the option of returning to your own home during the day) plans, in favour of developing individualized supports. The reasons for not pursuing these options were rational and sound, but again an opportunity may have been lost for new knowledge to be gained. Overall, while the Genio programme is innovative and novel in an Irish context, there may be a conservative mood running through the sites linked to a fear of failure should









# Lessons for Public Policy

**THIS REPORT** covers the first year of operation of the Genio dementia programme in Ireland. The latter seeks to develop and test new service models that might improve the range and quality of community-based supports for people with dementia. What we have seen in the first year of operation of the programme is that this objective has largely been met. New service models are in place and the lives of people with dementia have improved in all sites as a result of the investment. It is clear that more has to be done and that not everything is working as it should, but infrastructure has been improved, new methods of working are in place and a holistic model for dementia care is emerging slowly in a system that has remained moribund for decades. The next question is what has been learned that might have an impact on public policy for dementia in the country? The upcoming National Strategy for Dementia will be a major milestone in dementia care in the country. Is there anything that can be gleaned from the operation of the Genio programme thus far that might be useful for future policy for dementia care in Ireland and in particular the upcoming strategy?

The current policy frame sees dementia largely in biological terms. People get the disease and face it, by and large, on their own within their families and, if they are very fortunate, with the support of appropriate medical teams and the Alzheimer Society of

Ireland. Policy makers also associate dementia with risk resulting in a bias towards institutional care where people with the disease can be cared for in a secure environment. It is as if people with dementia are somehow deficient, pitiful, and deserving of exclusion from mainstream society, if not from their families.

The policy frame that underpins the Genio programme is different: the emphasis is on the collective and the social within a community-based environment; capabilities, assets, and inclusion are the principles underpinning the approach. Reconfiguring the paradigm for dementia in Ireland in this way would allow for the potential of the upcoming strategy to be fully realised, thereby becoming genuinely liberating for people with the disease and their families. An alternative policy frame would not necessarily cost any more money to develop and implement, but it would help to establish the primacy of the person with dementia in the decision-making process.

What would this counter policy frame look like? Moving towards a collective focus would lead to the disease becoming more public, more mainstream, more visible, and more explicit. For that to happen, information, knowledge, persuasion, anxieties, and greater public awareness of the disease must become part of the normal discourse on dementia, in the same way as people now talk knowingly

“ AN ALTERNATIVE POLICY FRAME WOULD NOT NECESSARILY COST ANY MORE MONEY TO DEVELOP AND IMPLEMENT, BUT IT WOULD HELP TO ESTABLISH THE PRIMACY OF THE PERSON WITH DEMENTIA IN THE DECISION-MAKING PROCESS. ”

and openly about cancer. Moving from biological to social would allow greater discussion of the meaning of attachment, place, identity, and relationships, thereby challenging families and communities to develop and maintain a communal approach to care that prioritises connectivity and mutual support systems. It would reinforce the need for, and benefits of, dementia friendly communities. This, in essence, is the same challenge as currently exists for the Genio dementia programme, which is to mobilise community resources in support of

early stages of the illness. People with dementia have physical, emotional and spiritual needs that require nurturing, through individualized supports and psychosocial interventions, if the various dimensions of personhood are to be realised. Sometimes this means taking chances with care structures and care processes that allow people with dementia to live as normally as possible in flexible, accessible and familiar environments that allow capabilities to be maximised. For the most part, people with dementia should live in their own homes where images of self

So far reconfiguration of local budgets within the Genio sites has been weak, but realignment must happen if we are to get what we say we want – home-based care for people with dementia. When people with the disease have to enter residential care, the emphasis should be on homely, small-scale, provision where biography and personality are central to the care process and autonomy is preserved as much as possible.

Seeing people with dementia as assets to be cherished can be of enormous transformative value to the society within which they live. People with dementia are citizens with inalienable human and civil rights that must be protected. They continue to have roles and relationships within families and communities that serve to enhance overall well-being and preserve the integrity of the human spirit – their own and others. A common theme running through the Genio sites is how much families value the person with dementia and how little external support they sometimes need to be able to continue caring for them. Sometimes people only want option demand – the knowledge that appropriate and individualised care will be available should they need it at some stage in the future. Through a focus on inclusion, people with dementia will become more visible in society leading to greater awareness of the disease and an acceptance of the need for a public response in the form of improved services and community-based support systems.

“ SEEING PEOPLE WITH DEMENTIA AS ASSETS TO BE CHERISHED CAN BE OF ENORMOUS TRANSFORMATIVE VALUE TO THE SOCIETY WITHIN WHICH THEY LIVE. PEOPLE WITH DEMENTIA ARE CITIZENS WITH INALIENABLE HUMAN AND CIVIL RIGHTS THAT MUST BE PROTECTED. ”

dementia care. This has not yet been fully realized across the four sites but remains an important objective of the programme. What the Genio programme is showing us, however, is that bringing together all the interested parties is possible and is a necessary, if not sufficient, condition for changing the culture and organization of care.

Replacing capabilities with risk would allow the potential of people with dementia to be realised during all stages of the disease, particularly in the

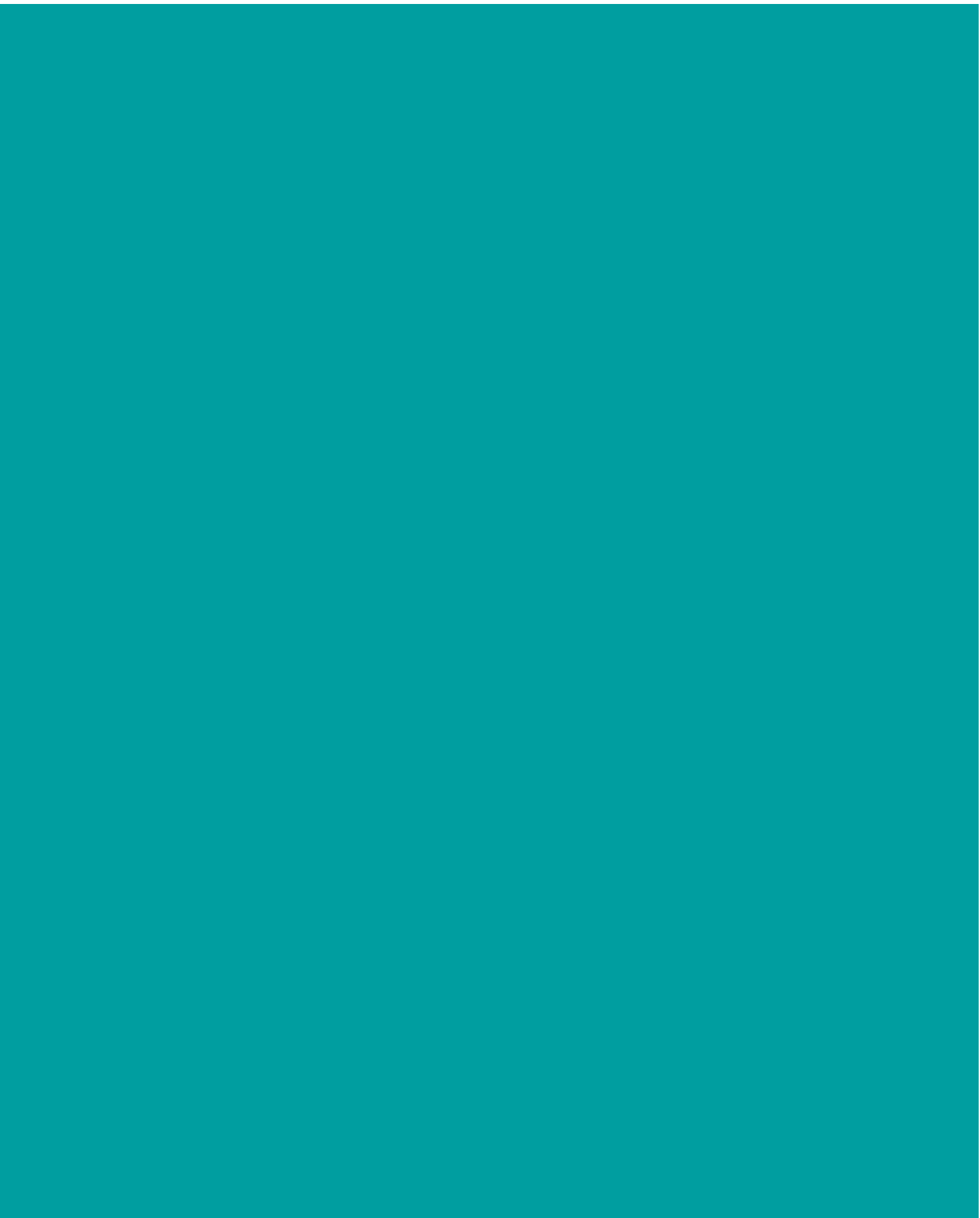
and identity are easier to preserve in the face of ongoing cognitive decline. For this to happen, dedicated, legislatively-based budgets must be made available to support individualized care packages that are focused on keeping people at home. Only when community-based spending on a person with dementia exceeds per capita residential care costs should consideration be given to admission to long-stay care and even then the financial bias should be towards keeping people with dementia living at home.

Even more fundamentally, adopting the counter policy frame for dementia outlined above can lead to a seismic change in how people think individually and collectively about the disease. This includes more enlightened personal attitudes and expectations about dementia, a new awareness and understanding of prevention and of the various stages of the illness and a recognition that dementia is the most important ageing question that society will face in the coming decades. Accepting the personhood of people with dementia means giving them a much more formal role in decision-making at the micro care level and the macro policy level. The Genio sites have some distance to travel to achieve this target in relation to dementia, but autonomy and empowerment, even when they have to be qualified, are key elements of personhood and identity. But for personhood to have real meaning it must be extended into citizenship whereby people with dementia are treated as full citizens with consequent rights and responsibilities. Living well with dementia requires an acceptance by society of the right of people with dementia to live at home in their own communities for as long as possible and practicable. The message of the Genio programme is that this can be achieved provided there is a commitment by government to recalibrate services, resources and funding towards person-centred and integrated community-based care delivered within informed, engaged and genuinely caring communities.

# Appendix A

## Genio Dementia Programme: Year 1 Evaluation Questionnaire

1. Programme objectives – briefly set out the initial objectives and any realignment that has happened in the past year.
2. Building relationships and setting up the consortium – was it easy/difficult? What is new about these relationships?
3. What is organisational form within the consortium? What is new about organisational form? How is the programme led/driven? Who are the leaders? Who are the key actors in driving change?
4. Integrating structures – map the relationships within the consortium and between the consortium and formal service providers and informal carers.
5. Outline the additions to the care landscape that have happened because of the investment – for example, detail the services, individualised supports, respite and technology that now exists directly as a result of your programme.
6. What has worked? Describe the top 3 successes. What measurement tools are being used to judge success?
7. What is the evidence of the impact – quantitative data, case studies, vignettes – show how these metrics provide compelling and convincing narrative.
8. Has any reconfiguration of resources/budgets taken place that reflects these successes? If yes, describe funding and resource allocation changes; if not, why not?
9. What has not worked? What has been the least successful aspect of the programme?
10. What have been main constraints to making progress – how have these been overcome/are being overcome/are difficult to overcome?
11. What are key priorities for 2014? How do you want to be assessed at end 2014?



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